Medication Adherence for Older Adults with Disabilities

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1. Introduction

Adherence to one's medication plan (i.e., taking the correct medication in the correct dosage at the correct time) is critical to maintaining health or keeping a disease under control, especially for long-term chronic diseases such as hypertension. Poor mediation adherence causes complications for patients (exacerbated symptoms, progression of conditions, and hospitalizations), and is estimated to cost billions of dollars of avoidable healthcare costs annually (Aitken, 2013; Iuga & McGuire, 2014). Increased rates of nonadherence have been reported for minorities and people with disabilities (Zhang & Baik, 2014). Lehane and McCarthy (2007) report conflicting findings evaluating the causes for nonadherence throughout the literature. Patients' perspectives about medication adherence, such as taking medications without anxiety, and concerns about side-effects are cited as potential contributors to intentional non-adherence (Iihara et al., 2004). A multiple pronged approach to understanding behavior and nonadherence is necessary to tackle this challenge.

While much research has been conducted on interventions to support higher adherence in patients (e.g., packaging solutions reminder systems, education), results have been inconclusive and often fail to understand the underlying reasons for nonadherence (Banning, 2009; Costa et al., 2015; Marcum, Hanlon, & Murray, 2017; Nieuwlaat et al., 2014). Furthermore, various adherence behaviors exist and simply categorizing patients as adherent or nonadherence is too simplistic. Research suggests that patients fall into one of three categories: adherent (infrequent to no missed doses), unintentionally nonadherent (forgetting doses), and intentionally nonadherent (actively choosing not to take doses) (Lehane & McCarthy, 2007; Lowry, Dudley, Oddone, & Bosworth, 2005; Wroe, 2002). The mixed evidence on intervention success combined with the evidence that there are at least three groups of patients suggests that a more

individualized approach needs to be taken to understand the root cause for nonadherence (Lehane & McCarthy, 2007; Marcum et al., 2017).

To this end, an in-depth and robust qualitative interview was created to assess the underlying motivations and mechanisms driving adherence behaviors. The participant group of interest is older adults (50 years or older) who have a long-term mobility or sensory impairment (e.g., Multiple Sclerosis, low vision, low hearing) that may now be aging into secondary disabilities. This is a unique and under-studied population as they are increasing in numbers due to improved healthcare. They face additional challenges compared to non-impaired older adults who experience normative age-related changes. This group could be used as a model for success in medication management as they have thrived in spite of long-term impairments. It could be that adults who have reached 50+ years with a long-term impairment recognize their health limitations and take their disease management more seriously than non-impaired older adults; this group does not take their health for granted. Investigating their motivations, abilities, and triggers for their medication management is important in understanding their success and how those elements can be leveraged to provide support to other groups who are not successful with their medication management. By understanding how and why some patients are successful in managing their own medications, interventions can be developed to support those who are not. Additionally, because an identical study using a non-disabled older adult population was run in parallel with this study, the results of the impaired population can be directly compared to those of the unimpaired older adults.

2. Purpose

This study was designed to understand medication management strategies of older adults with disabilities so that barriers to adherence can be identified and interventions can be developed to help support those who have issues with adherence. Specifically, this study aimed to examine how medication adherence in this population differs from older adults without long-term disabilities and identify the issues with accessibility for extant mediation adherence interventions and technology solutions.

3. Method

3.1 Participants

Twenty-six older adults (13 female) with long-term disabilities participated in this research study (Mage = 61.9 years, SD = 9.3; Range: 52 – 88). To be eligible to take part in this study, participants had to be fluent in English, age 50 or older, have a sensory or physical impairment that began before age 50, and be taking at least 3 medications and responsible for managing their own medications. Participants included individuals with mobility impairments (n=10), vision impairments (n=10), and hearing impairments (n=6). Participants had, on average, 3.7 medical conditions requiring medications (SD= 1.2; Range: 2-6) and took an average of 5.7 medications (SD= 2; Range: 3-9).

3.2 Materials

The interview guide was created internally and designed to gain an understanding of participants' daily lives and medication routines. The medication knowledge and inventory questionnaires were also developed internally to capture participants' understanding of their

medications. Morisky Medication Adherence Scale (MMAS) is a tool to assess medication adherence (Morisky, Ang, Krousel-Wood, & Ward, 2008) chosen here for its wide use and brevity. All other questionnaires were selected as a basis for gaining knowledge and insight into participants' medication routines, daily living, or technology use.

3.2.1 Interview Guide

- Walk through daily routine
- Triggers
- Tools
- Motivations
- Frustrations
- Barriers
- Reasons for missed meds
- Living with medical conditions

3.2.2 Questionnaires

- Demographics
- Morisky Medication Adherence Scale
- Medication Adherence Confidence
- Medication Importance, Ease of Use (Summary Information)
- Medication Knowledge
- Medication Inventory
- Technology Experience Profile
- Technology Adoption Style

- Life Space Questionnaire
- Short Portable Mental Status Questionnaire
- Happiness and Flourishing
- Quality of Life
- Temperament Test

4. Procedure

Qualitative approach allows for a deep dive to investigate this research question. Researchers visited each participant in their home. Participants described their daily medication routine with the researchers, including details about what exactly they did to take their medications, where in the home the medications were kept, as well as the type of container that was used to store the medications. Participants also rated the effectiveness of their strategies during routine and non-routine days. Conducting interviews in the participant's home allows the researchers to understand the context in which participants must adhere to their medication regimen as well as provides participants with the cues and methods that they use on a daily basis.

5. Results

5.1 Daily Routine

In order to gain an understanding of the individual and their medication routine, the first component of the interview was the daily routine and medication trigger portion. Participants were guided through various types of days (a typical day at home, a day spent on-the-go, travel days, etc.) and were questioned about all factors that influenced their medication routines (medication location, medication trigger, trigger effectiveness, etc.). Table 1 shows the trigger

codes and their definitions that were used to code participants' responses. These codes were developed using a bottom-up, data-driven approach, as well as incorporating cues, triggers, and strategies from literature (Boron, Rogers, & Fisk, 2006).

Table 1. Trigger codes and descriptions.

Trigger Code	Description
SIMPLE REMINDER-BASED	
C-MED	See the medicine container
C-REM	See a reminder like a sticky note
HEAR	Hear an audio reminder (like a text or alarm)
FEEL-MED	Feel the medicine (e.g., in pocket)
TIME-BASED	
CLOCK	Seeing the clock reminds them
MEAL	Meal time
ROUTINE	Other part of daily routine
LOCATION-BASED	
PLACE	Walking into a certain room reminds them
PERSONAL-BASED	
HEALTH	Don't feel well
MIRROR-BASED	
C-ACT	See someone taking their medication
C-HEALTH	See someone else feeling bad
INTERACTION-BASED	
PERSON	Someone intentionally reminds them
TALK	Medication/disease comes up in conversation
OTHER	
OTHER	

The most frequently cited triggers were time-based triggers- routine, meals, and clock (used 47% of the time). The most common trigger was routine (used 33% of the time). When looking only at the more effective triggers (triggers that successfully prompt medication adherence at least 95% of the time), time-based triggers still come out on top, again comprising 47% of all triggers, with routine once again used one-third of the time. By comparison, the unimpaired older adult participants had a tie for the most frequently cited trigger- seeing the

medication container and routine were each used 24% of the time. This suggests that while the general population often relies on happenstance (seeing the medication container) to trigger a medication event, the disabled older adults are more likely to actively build adherence into their daily lives.

Most participants experience routine, typical days the majority of the time or reported building their medication routines into the routine portion of their days (i.e., those who work or are on the go during the day take medications in the morning or before bed when they're always at home). However, when participants are traveling or out of the home in non-routine ways, they reported having to alter their triggers in order to maintain adherence. On these instances, participants try to remember to pack travel containers or carry their medications in their clothing or wheelchair pockets. As long as they remember to bring their medications out of the home, they generally remember to take the medication at the appointment time.

5.2 Medication Adherence Scale

Participants' medication adherence was assessed with the Morisky Medication Adherence Scale (MMAS; Morisky et al., 2008). The MMAS is an 8-item measure that assigns scores of high (score= 0), medium (score= 1-2), or low adherence (score> 2). The items are listed in Table 2. Participants on average scored low adherence (M= 3.2, SD= 2.1; Range: 0-8. For comparison, the unimpaired participants on average scored in the medium adherence range (M= 2.1).

Table 2. Morisky Medication Adherence Scale (MMAS).

Do you sometimes forget to take your medicine?	**YES**	**NO**
People sometimes miss taking their medicines for reasons other than forgetting. Thinking over the past 2 weeks, were there any days when you did not take your medicine?	**YES**	**NO**

Have you ever cut back or stopped taking your medicine without telling your doctor because you felt worse when you took it?	**YES**	**NO**
When you travel or leave home, do you sometimes forget to bring along your medicine?	**YES**	**NO**
Did you take all your medicines yesterday?	**YES**	**NO**
When you feel like your symptoms are under control, do you sometimes stop taking your medicine?	**YES**	**NO**
Taking medicine every day is a real inconvenience for some people. Do you ever feel hassled about sticking to your treatment plan?	**YES**	**NO**

How often do you have difficulty remembering to take all you medicine?

◯ Never/rarely

◯ Once in a while

◯ Sometimes

◯ Usually

◯ All the time

5.3 Intentional vs. Unintentional Nonadherence

In order to explore the idea of intentional versus nonintentional nonadherence, participants were asked how often delayed doses were intentional (e.g., "I'm busy right now, but I'll take it later") and how often they were unintentional (e.g., "I can't get the pill bottle open, but I'll ask my daughter to open it when she comes over later"). While 42% of the non-disabled participants responded that late doses were always unintentional, 76% of the disabled participants ascribed to always being unintentionally nonadherent. Conversely, the non-disabled participants indicated that 23% of late doses were always intentional, while only 4% of the disabled group cited always intentionally delaying doses. This suggests that despite an understanding of the negative consequences of nonadherence, the disabled population has a lack of control over their medication adherence. Rarely are these individuals choosing not to take a dose; rather, they're

unable to adhere the way they should. Figure 1 shows the breakdown of participants who report intentional vs. unintentional late doses.

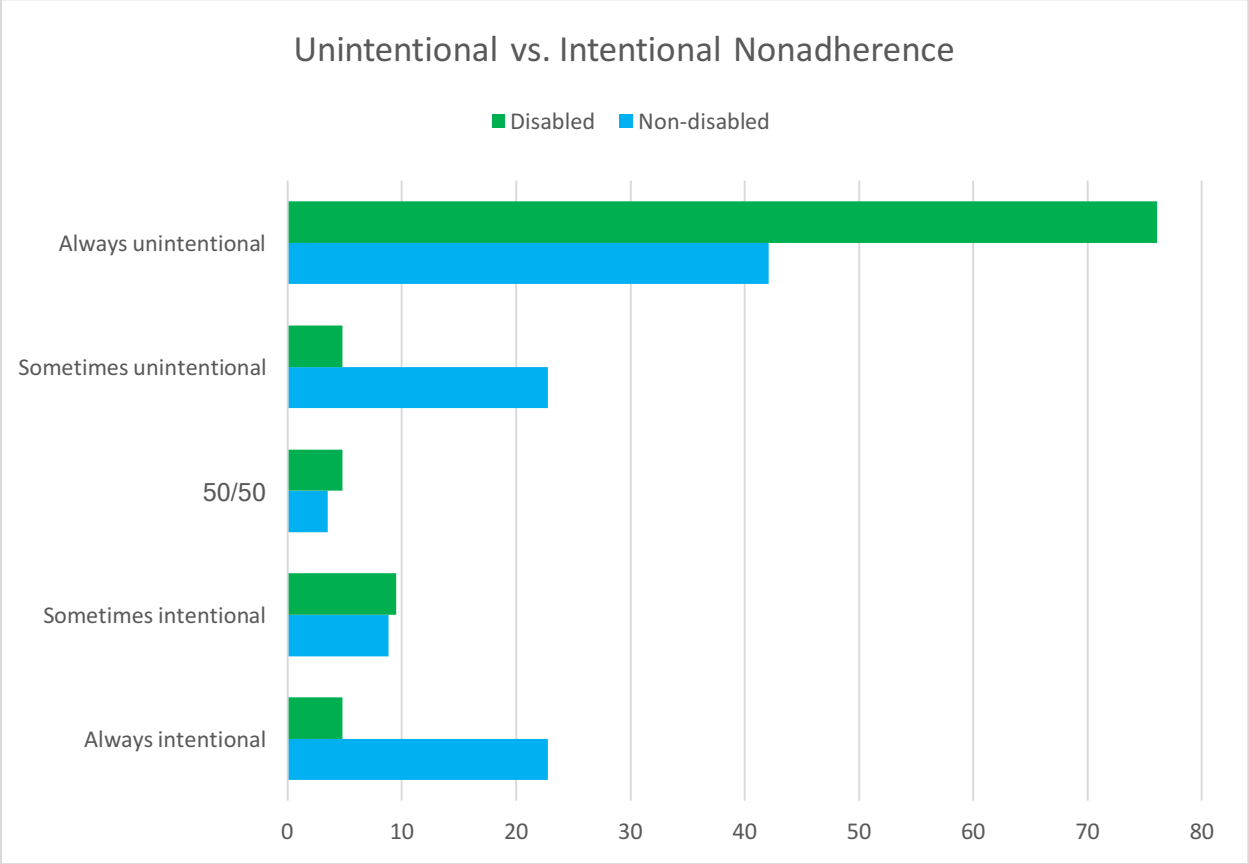

Figure 1. Unintentional vs. intentional nonadherence by percentage of total sample.

5.4 Motivations

Participants were asked to describe their motivations for taking their medications and their motivations for not taking their medications. Across the board, both the non-disabled and disabled populations cited hope of becoming or staying healthy as the number one motivation, followed by desire to avoid symptoms or pain. Unlike the non-disabled population, the disabled population frequently cited fear-based motivations, such as fear of a relapse or fear of going to the hospital. These individuals recognized that the loss of other functions on top of the primary

disability could be catastrophic; a deaf participant reasoned “I want to hold on to my vision. If I had a stroke I wouldn’t be able to use my hands and wouldn’t be able to sign. A friend had paralysis and was not able to make facial expressions. Face and body language are important in the deaf community.” A vision-impaired participant stated that he took medications consistently so that he could retain the limited vision that he has and prevent himself from becoming fully blind.

Participants were also asked what (if anything) motived them to not take their medications. While the majority of the non-disabled population (52%) had at least one motivation for not taking a prescribed medication dose, only 23% of the disabled population cited a nonadherence motivation. For the non-disabled population, the most frequently listed nonadherence motivation was wanting to avoid side effects caused by the medication (such a frequent urination or dizziness). The number one reason for not taking a medication for the disabled population was fear of long-term side effects or harm caused by the medication. As the non-disabled population is motivated by current discomfort, the disabled population is thinking ahead to long-term effects on health.

5.5 Barriers

Participants were asked to discuss any barriers, complications, and/or frustrations they encountered during their medication routines. Some frustrations were common across all three types of disabilities (e.g., prohibitive cost of medications, overwhelming feeling of taking so many medications, squeezing eye dropper bottles or opening child-proof bottles), but others were unique to each group. For those individuals with mobility impairments, running out of medications/obtaining refills was the top barrier to adherence. For participants with vision

impairments, the logistics of organizing medications and obtaining the correct medication at a given time was the biggest frustration. There were no unique barriers for the hearing-impaired group. When asked what would make taking their medications easier, the most frequent responses were a better organization system (30 day pillbox, a packet of meds for each dose time, etc.), some sort of reminder (with a vibrating or light option for the hearing-impaired), and longer prescriptions from physicians and pharmacies (e.g., a full years' worth).

5.6 Medication Adherence Assistive Technology Accessibility

As part of the current study, the usability and accessibility of common technologies designed to improve medication adherence were evaluated. Medication adherence technologies can be divided into the following categories: instrumented pill containers, educational videos, smartphone applications, and text based reminders. Human factors experts obtained exemplars of each category and reviewed the usability and accessibility of each exemplar. The reviews were based on conformance with common technical standards such as the technical requirements associated with Section 508 of the Rehabilitation Act (add reference), the Web Content Accessibility Guidelines (WCAG), and the Human Factors Design Standard (HFDS).

The first category of products consisted of instrumented pill containers. Typically, an instrumented pill container detects when a bottle has been opened and compares the opening with a pre-loaded medication schedule. If the bottle has not been opened at the scheduled time the bottle can generate an audio / visual alert or generate an electronic message alerting the user and/or care givers that a dosage has been missed. A number of potential usability and accessibility issues were noted.

1. **Instrumented pill bottles may be difficult to handle.** Typically, the instrumentation and associated electronics require additional space when increases the bulk and weight of the pill bottle. Users with fine motor control impairments or users with a loss of strength in their hands may find the pill containers bulky and difficult to manipulate.
2. **Pills must be transferred from the standard pill bottle to the instrumented bill bottle.** An additional task is required in order to utilize the technology. Users must remember to transfer the contents of prescription bill bottles to the instrumented pill bottles. In addition, the labeling must be transferred or duplicated as well. Users with cognitive limitations may forget to perform the transfer or may make errors in duplicating the prescription information. The potential for human error is great particularly if the dosage instructions or identification of the pill bottle contents is transferred incorrectly.
3. **Users may not see visual alerts.** The visual alerts generated by the instrumented pill bottles may be insufficient for users with impaired vision. Users may have difficulty seeing the visual alert unless they are very close to the pill bottle.
4. **Users may not hear the auditory alerts.** Some of the auditory alerts are not very loud. Users with impaired hearing may find it difficult to hear alerts because the alerts are insufficiently loud. Users with limited hearing may find it difficult to localize the alerts and identify which specific pill bottle is generating the alerts.
5. **Programming instrumented pill bottles may be inaccessible.** Users are required to input the medication and medication schedule details into a mobile application or a web page application. Users that are blind may find it impossible to input the

required information due to the inaccessibility of the supporting application. The application may not be designed for operation with screen reader technologies such as Voice Over or JAWS. If the applications were inaccessible, users that are blind would be dependent on assistance from a sighted user in order to input new medications or change the information associated with existing medications.

Educational videos tailored to the specific illness or medication that the individual is taking may also increase medication adherence. The tailored videos discuss the benefits of consistently taking the medications as prescribed and discuss the consequences of failing to follow the medication schedule. The videos provide contextual relevant information in an easy to understand format. However, some users with disabilities may find it difficult to access the information.

1. **Videos may not be closed captioned.** Users without hearing rely on captions in order to obtain the information contained in the audio. Some videos may not be captioned or may be captioned incorrectly generating incompatibility with the user's chosen method of playback.
2. **The captioning method may make it difficult to obtain information.** Captioning that is embedded in the video itself scales with the video. Captions from videos played back on a mobile device may be so small that users are unable to read the caption. Captions that do not have the appropriate level of contrast between the foreground and the background may be difficult to read.
3. **Locating tailored videos may be difficult or impossible due to inaccessible video hosting.** Search mechanisms or lists of videos may be inaccessible making it difficult

to use a screen reader to locate content. Web sites hosting the videos may be inaccessible or videos embedded in mobile applications may be inaccessible.

Smartphone applications can track medication schedules and provide reminders at the appropriate times. When users use the application for the first time they create an account that contains personal information as well as the names and dosages of the medications that they are taking. In addition, the input additional information about each medication such as when the medication should be taken, instructions such as "take with food", and additional user specific warnings. The application then tracks medication adherence by asking if the user took their medication and generating alerts if the user does not respond or indicates that they have not yet taking their medication. Users with disabilities may find the mobile application difficult to use.

1. **Mobile applications may not be fully compatible with screen readers.** Some applications may not be fully compatible with VoiceOver or other screen reader technologies. Blind users trying to navigate the application may find that some content is inaccessible to them or that the existing content is difficult or confusing to navigate.
2. **Users may not have the mobile device nearby when the alert is received.** Some older adults are not in the habit of keeping their mobile phone near them at all times. The phone may be stored in a purse or on a dresser until the user needs to use the device. If an alert is received while the user is not near the mobile phone the user may not receive the alert in a timely fashion. Some older adults choose not to keep their smart phones powered unless in use. Remembering to routinely charge their

phones may be a burden and they would prefer to know that they will have sufficient power when the phone is actually needed. Alerts and other indications will not be received when the phone is not powered.

3. **The application may be too complex for older users.** The complexity of some medication adherence applications is complicated and difficult for older adults to navigate. Users with cognitive impairments or users with limited vision may find that the user interface complexity is prohibitive.

The final category of medication adherence tools is text-based reminder services. Users input the contact and medication information by either calling the service and providing the information over the phone or by using a website or mobile application to setup the service. When the service determines that it is time for the user to take their medication they provide a text alert to the user and asks the user to indicate whether they have taken their medication. If the user fails to respond or indicates that have not taken their medication other members of their care team may be alerted. Knowing that other care team members will be notified if they do not take their medication at the appropriate times may motivate some users to take the medication as prescribed.

1. **Setup may be inaccessible to some users.** Users without vision may have difficult setting up the service if the web site or mobile application associated with the service is inaccessible. Subsequent usage of the service may be delivered in an accessible format but users may find that the initial setup of the service is inaccessible to them.
2. **Users may not have the mobile device nearby when the text message is received.** Some older adults are not in the habit of keeping their mobile phone near them at all

times. The mobile phone may be stored in a purse or on a dresser until the user needs to use the device. If a text message is received while the user is not near the mobile phone the user may not receive the text message in a timely fashion. Some older adults choose not to keep their smart phones powered unless in use. Remembering to routinely charge their phones may be a burden and they would prefer to know that they will have sufficient power when the phone is actually needed. Text messages will not be received when the phone is not powered.

6. Conclusion and Recommendations

Older adults aging with a long-term disability represent a population with unique challenges when it comes to medication adherence. On the surface, this group has worse adherence than a non-impaired sample (according to MMAS scores), but a closer look reveals a more complex picture. The disabled sample are much more likely to be unintentionally nonadherent, compared to an intentionally nonadherence non-disabled population. Rather than purposely delaying medication doses, this group is likely to be unable to take medication at the appropriate time due to physical limitations. Examining underlying motivations for adherence indicated that these individuals have a thorough understanding of the consequences of nonadherence and a fear of worsening or new medical conditions. By understanding both the barriers to adherence and unique accessibility issues for each type of disability (mobility, hearing, vision), interventions can be designed to target the difficulties for each group. This population would likely be highly motivated to implement interventions to their medication routines because of the importance they place on adherence.

While this sample has lower adherence compared to a sample of non-disabled older adults, evidence creates a picture of individuals who want to adhere and are impeded by physical limitations. In general, this group is unlikely to greatly benefit from education-based technologies as these individuals tend to be well educated on both their medications and medical conditions. However, this sample could greatly benefit from organizational, reminder, and tracking technologies. Across all types of disabilities, participants reported feeling overwhelmed by taking so many different medications and opening child-proof pill bottles, and vision-impaired participants noted difficulty organizing and obtaining the correct medication at a given time. An accessible instrumented pill box would likely help participants across the board and those with vision impairments in particular. Instrumented pill boxes could ease the stress of managing multiple medications by creating an organized system. Instrumented containers with automatic pill dispensers or timed compartment openings would greatly aid visually-impaired individuals who may not be able be able to correctly identify pills by sight. Reminder-based technologies that have accessible solutions for all disability types would benefit all participants, particularly those who mentioned that they sometimes forget a dose. Last, tracking technologies could allow participants to see instances they tend to miss a dose and potentially allow those individuals with concerned family track adherence as well.

Technology may significantly contribute to greater adherence; however, this research suggests that other considerations may be just as important. For example, physicians should discuss possible side effects and the impact they may have on the quality of life for the individual aging with a disability. An increase in the frequency of urination may discourage adherence particularly if individual faces mobility challenges that make bathroom transfer difficult. An increase in nocturia, needing to urinate at night, can be particularly troublesome for

those that have difficulty transferring from the bed to a mobility aid. Individuals without accessible transportation may have difficulty in refilling routine medications. Physicians should be aware of transportation issues and adjust refill schedules if possible to accommodate people with disabilities. The medical community seems to be effectively communicating the value of medication adherence to this audience but lacks in understanding of the underlying factors that might influence adherence. Future research should focus on a system level solution to medication adherence for this population taking into account medication cost, suitability, availability, transportation, and technologies designed to assist in the management of complex medication regimes.

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